CHAPTER 1

INTRODUCTION AND ORIENTATION TO THE STUDY

1.1 INTRODUCTION

In this chapter an overview of the research is presented in the form of the background and motivation of research, rationale of the research, the statement of the problem, research objectives, significance of the research, paradigmatical perspective, research model, research design, research methodology, ethical considerations of the research as well as division into chapters.

Mental retardation/Mentally defective means that “their brain has been damaged from an accident, illness or since birth and that they have low mental abilities” (Cambridge International Dictionary 1996:887).

During the first half of the twentieth century, the tendency was to “put away” the mentally ill and the mentally retarded into institutions.

Since the 1960`s the tendency of institutionalization has been reversed and de-institutionalization has become the latest trend, which is now a problem. This research is of great importance as the mentally retarded patients may be de-institutionalized without the necessary services and facilities to cater for their needs in the community of

District 22 (sub-district 222), KwaZulu-Natal.

Since this research is about the needs of the mentally retarded, it is important to know the classification of the mentally retarded and intelligence by intelligence quotient range.

Table 1.1: Classification of intelligence by IQ range

(Shanley 1991:4)

CLASSIFICATION	I.Q. RANGE
Profound mental retardation	Below 20 or 25
Severe mental retardation	20-25 to 35-40
Moderate mental retardation	35-40 to 50-55
Mild mental retardation	50-55 to approximately 70

In the next section, the background information, which led to this research will be discussed.

1.2 BACKGROUND OF THE RESEARCH PROBLEM

The treatment of the mentally retarded internationally will be discussed before zooming into the problem in South Africa and in the community of District 22 (sub-district 222), KwaZulu-Natal.

In Britain before the Industrial Revolution, people lived mainly in rural areas and in small villages with extended families who maintained themselves agriculturally. The mentally retarded were accepted as part of the household and taken care of by their families or left to their own devices (Maulin, Race & Jones 1980:38).

With the Industrial Revolution from 1750 until 1900 came about large towns, with people increasingly crowding together at the local factory or mill. Together with this came the measurement of people by their ability to cope with the new technological and commercial processes. Demands for better education became necessary as the need for the more abstract skills of reading and writing became an imperative if any social status was to be achieved. With these developments, the mentally retarded person's low competence became obvious. There prevailed an optimistic attitude, however toward their educability and their presence in the community was accepted (Maulin et al 1980: 38).

Presently, throughout the United Kingdom, great strides have been made towards comprehensive community-based services. Progress varies in different regions.

National policy in England and Wales is to close all large mental handicap institutions and develop community support networks, but progress is delayed by limitations on public spending, as well as problems of leadership and management (Walter, Hollard & George 1991:501).

In the United States and Australia, there is a great variety of service provision at State level and below. East Nebraska and West Massachusetts have pioneered community services of great imagination and commitment, but many patients remain in their large institutions (Walter et al 1991:501).

Western Australia has achieved a service without any large institutions, with residential

care being largely in ordinary-type homes.

Queensland, a province of Australia is following suit, with a rapid shift of philosophy and policy towards community-based services.

In Canada, this process has gone further and more generally, with “cost sharing” encouragement at federal level (Walter et al 1991:501).

In Denmark and Sweden, recent decentralization of management has been associated with policies of integration into “normal” services, together with provision for personal advocates. Norway has been developing multi-disciplinary teams (Walter et al 1991:501).

In South Africa, Primary Health Care, being one of the alternatives is now being propagated as the main emphasis of the present health care system (African National Congress 1994:20).

The transformation process in this country accelerated after the first democratic elections took place in 1994 and the African National Congress came into power nationally. In seven of the nine provinces, new and idealistic policies have been set out and developed by the new government, on all fronts, including health. A policy to promote primary health care has been adopted in the health section.

The challenge however, that lies ahead is to bring the “new and idealistic” policies into practice with the limited resources. The resources are limited in that it might be difficult to convince policy makers of the importance of putting additional resources into psychiatric / mental health care.

Psychiatric and mental health services are often not seen as a priority in comparison with

popular cases such as maternal and child services or more dramatic problems such as HIV/AIDS (Uys 1997:25-28).

The mentally retarded/handicapped people are seen by many in society as people with low status as they contradict western social values and harms such as low I.Q., limited productivity, various perceptual motor and often physical and sensory deficits, features of poor learning ability and memory, limited attention span, the need for supervision and often physical deformity (Park 1991:111). It is due to this "low status" that families with a mentally handicapped member often experience great social stigma and discomfort, which is a reflection of the broader values of society as a whole. Consequently, some families also experience a need to be free and also experience difficulty from the responsibility of caring for such a child or family member in the community. (Park 1991: 112).

South Africa is approximately 20-25 years behind the European and Scandinavian countries, which have followed and developed the principles of "normalization" and "communalization" of the mentally handicapped so that they are integrated with people in the general community (Park 1991:111-112).

However, in South Africa, institutionalization still exists as a predominant long-term management approach to the mentally handicapped, even in instances where the intellectual and or adaptive potential of the person is sufficient to enable him to remain in the community with a degree of supervision (Park 1991:112).

Therefore, in South Africa this situation is particularly in need of attention because the

families need for institutional care for their handicapped child or family member is often very strong. The process of institutionalization exacerbates the adaptive functioning of the mentally handicapped as they already have problems with their adaptive ability . Some of the features of institutional life are depersonalization, enforced life structure, loss of control over personal life, loss of contact with family and the outside world, loss of prospects outside the institution, staff-patient hierarchy and the ward atmosphere (Park 1991:112).

A research psychologist at the University of Cape Town set out to do an epidemiological survey of Khayelitsha, and was surprised to find that the community placed mental illness near the top of it's list of most pressing health problems. The Khayelitsha community requested urgent assistance, particularly with child and adolescent psychological problems, as the psychiatric services in the area were too thinly spread to absorb the high level of mental ill health (Strachan 2000:8).

This then was the beginning of the Empilweni (Place of Healing) Project, which train community mental health workers (six months of intensive academic and practical training) to skillful counselors with enough psychiatric knowledge to take on most of mental problems. The problems included depression, anxiety and mental handicap to sexual and physical abuse (Strachan 2000:8).

The aim of the project was to provide counseling and support to families and to educate the wider community about mental health problems in disadvantaged areas.

Due to this project, it was found that the community mental health workers were more in

touch with problems, there are fewer barriers and they are in a better position to play a preventative role than the clinically- based psychiatric nurses (Strachan 2000:8-9).

One of the directives for implementing the overall plan in the "National Health Plan for South Africa" by the African National Congress was "Improving the provision of community care, rehabilitation services and education of the mentally ill people" (African National Congress 1994:47). These promises have not been delivered as yet, as there have been no changes with regard to improving the provision of community care, rehabilitation care, rehabilitation services and education of the mentally ill people.

The Mental Health Care Bill of 2001 (chapter 11:8-10) state the objectives, as to regulate the mental health care in a manner that makes the best possible mental health care, treatment and rehabilitation services available to the population equitably, efficiently and in the best interest of mental health care user's.

The Mental Health Care Bill of 2001 (chapter 11:12) does not make any provision for the in-patient care of the mildly and moderately mentally retarded patients in the community.

The Mental Health Care Bill of 2001 (chapter11:7) state that Care and Rehabilitation Centers may –

(b) " provide care, treatment and rehabilitation services to persons with severe or profound intellectual disabilities."

This has a direct bearing on the policies of de-institutionalization and total integration of the mentally retarded in the community.

It would therefore seem that the mildly and the moderately mentally retarded will be provided with mental health care, treatment and rehabilitation services at primary level as stated in the Mental Health Care Bill.

The Mental Health Care Bill of 2001 (chapter 11:6 a and 6 b) also states that the health service in implementing the policies “must promote provision of community-based care.”

Umgeni Care and Rehabilitation Centre is part of the Midlands Complex which comprises the following hospitals and number of beds :

Table 1.2: Hospitals/Care Centres in the Midlands Complex

HOSPITALS/CARE CENTRE	BED STATE
Town Hill Hospital, Pietermaritzburg	568
Fort Napier Hospital, Pietermaritzburg	458
Umgeni Care & Rehabilitation Centre	624

Umgeni Care and Rehabilitation Centre is situated in Howick, a rural area in District 22 (sub-district 222) KwaZulu-Natal.

Howick is situated about 25 kilometers from Pietermaritzburg. Umgeni Care and Rehabilitation Centre at present provides for the care and treatment of 478 mentally retarded patients of all races and all ages including some patients who also suffer from organic brain damage or the after effects of trauma.

A number of mentally retarded patients, who are state patients or who are also mentally ill, and cannot be managed at Umgeni Care and Rehabilitation Centre, are also hospitalized at Town Hill and Fort Napier Hospitals, where the medical officers are more readily available and where closed wards also exist.

Town Hill and Fort Napier Hospitals accommodate mentally ill patients of all races who are acutely and chronically ill, including geriatric, forensic and state patients.

The following are statistics compiled by the researcher regarding the discharges from Umgeni Care and Rehabilitation Centre from July 2000 to July 2002.

Table 1.3: Discharges from Umgeni Care & Rehabilitation Centre

DISCHARGES FROM UMGENI CARE AND REHABILITATION CENTRE							
YEAR	**CERTIFIED PATIENTS**			**CONSENT PATIENTS**			**TOTAL**
DISCHARGED	**MALES**	**FEMALES**	**TOTAL**	**MALES**	**FEMALES**	**TOTAL**	
JULY 2000 – DEC. 2000	**1**	**0**	**1**	**5**	**1**	**6**	**7**
JAN. 2001 – JUN. 2001	**2**	**1**	**3**	**6**	**1**	**7**	**10**
JULY 2001 – DEC. 2001	**0**	**1**	**1**	**2**	**2**	**4**	**5**
JAN. 2002 – JULY 2002	**0**	**0**	**0**	**3**	**0**	**3**	**3**
TOTAL	**3**	**2**	**5**	**16**	**4**	**20**	**25**

The researcher also compiled statistics from the admission and discharge register of Umgeni Care and Rehabilitation centre on the patient discharges to the community from July 2000 to July 2002 as shown in Table 1.4:

Table 1.4: Patients discharged: July 2000-July 2002

PATIENTS DISCHARGED: JULY 2000 – JULY 2002	
SUPPORT SYSTEM DISCHARGES INTO THE COMMUNITY	**NUMBER OF PATIENTS**
Into parental care on their request	16
Other care & rehabilitation centers	2
Town Hill & Fort Napier hospitals	7
Reclassified from certified to consent patients	4
TOTAL	29

It is within this background that this research attempts to make a contribution to the understanding of the problems relating to de-institutionalization in KwaZulu-Natal. In the next section, the reason for undertaking this research will be highlighted.

1.3 RATIONALE OF THE RESEARCH

- The mentally retarded patients used to be institutionalized.
- This now has changed due to the following reasons:

1) The Mental Health Care Bill of 2001(chapter 11:12) states that the mental health

care user is entitled to voluntary care, treatment and rehabilitation services as an out/in patient unless the mental health care user is **severely** or **profoundly mentally disabled**. No provision is made for the **mildly and moderately mentally disabled**.

2) The mentally retarded cannot however merely be placed in the community without knowledge of their needs and what facilities and services are available in the community of District 22 (sub-district 222), KwaZulu-Natal, to care for them.

3) **No research** has been done on the **needs** of the mentally retarded patients in the community of District 22 (sub-district 222), KwaZulu-Natal.

4) The appropriate availability of **resources/facilities** in the community of District 22 (sub-district 222), KwaZulu-Natal, for the mentally retarded are not known.

5) It is therefore of utmost importance to do this research:

   - on the needs of the mentally handicapped patients in the community of District 22 (sub-district 222), KwaZulu-Natal and
   - on the facilities and services that are available in the community of District 22 (sub-district 222), KwaZulu-Natal, so that the process of de-institutionalization can be successful.

The statement of the problem should be the next heading.

1.4 STATEMENT OF THE PROBLEM

The Mental Health Care Bill of 2001 (chapter 11:12) does not make any provision for the mildly and moderately mentally retarded. They are not even mentioned in the Mental Health Care Bill. These patients have lived in institutions and are now going to be forced to live in the community without any scientific knowledge of what their needs are, and whether services and facilities are available to see to their needs.

1.5 AIM OF THE RESEARCH

In light of the above mentioned statement, the aim of the research is to explore and describe the needs of the mentally retarded patients and to explore the facilities and services available in the community of District 22 (sub-district 222), KwaZulu-Natal. The aim of the research can be "broken down" into the following research objectives:

1.6 RESEARCH OBJECTIVES

The specific objectives of this study is to:

- Explore and describe the physical, emotional, financial, psychological, social, educational, spiritual, and cultural needs of the mentally retarded patients living in the community of District 22 (sub-district 222), KwaZulu-Natal.
- Explore and describe the services and facilities which are available for the mentally retarded patients living in the community of District 22 (sub-district 222), KwaZulu-Natal.
- Make recommendations to the Department of Health to ensure the de-

institutionalization process is successful in the community of District 22 (sub-district 222), KwaZulu-Natal.

1.7 RESEARCH QUESTION

From the problem statement, the following research questions can be derived

- What are the physical needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What are the emotional needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What are the financial needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What are the psychological needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What are the social needs of the mentally retarded patient living in the community of Disrtict 22 (sub-district 222), KwaZulu-Natal?
- What are the educational needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What are the spiritual needs of the mentally retarded patient living in the community of District 22 (sub-district 222, KwaZulu-Natal?
- What are the cultural needs of the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?
- What services and facilities are available to the mentally retarded patient living in the community of District 22 (sub-district 222), KwaZulu-Natal?

- What recommendations could be made to make the de-institutionalization process successful in the community of District 22, KwaZulu-Natal?

1.8 SIGNIFICANCE OF THE RESEARCH

No research findings could be found that has been done on the holistic needs of the mentally retarded patients in the community of District 22 (sub-district 222, KwaZulu-Natal.

Knowledge acquired from research done in other countries on this topic indicated that it was imperative to explore and describe the needs, the services and facilities available for the mentally retarded patients for successful de-institutionalization of the mentally retarded patients in the community of District 22 (sub-district 222), KwaZulu-Natal. The findings of this research will facilitate in the future planning of the de-institutionalization process and the caring of the mentally retarded patient in the community of District 22 (sub-district 222), KwaZulu-Natal.

1.9 OPERATIONAL DEFINITION OF CONCEPTS

- **Needs.**

Needs are the things identified as a gap between what is evaluated as a necessary level or condition by those responsible for the mentally retarded for this assessment and what actually existed.

The needs that have been identified in this research are physical,emotional, financial, educational, spiritual, psychological, cultural and social needs.

- **Needs assessment.**

Needs assessment refers to the process where the needs of the mentally retarded patients, who live in the community of District 22 (sub-district 222), KwaZulu-Natal was studied, analyzed and was provided to the Department of Health to help for future planning for the mentally retarded and the process of de-institutionalization.

- **De-institutionalization.**

De-institutionalization means removing thementally retarded, who do not belong in institutions, from institutional life and putting them in the community where their physical, psychological, social, educational, financial, cultural and spiritual needs are met by making alternative arrangements.

- **Mental retardation.**

For the purpose of this research, the mentally retarded and mentally disabled, have the same meaning and refers to all persons who have a low intelligence quotient and who live in the community of District 22 (sub-district 222), KwaZulu-Natal.

- **KwaZulu-Natal.**

KwaZulu-Natal is one of the nine provinces in South Africa. It is divided into 7 sub-districts (sub-district 221 to sub-district 227) and has a total population of 947672 people. Sub-district 222 was used in this study

- **Community.**

For the purpose of this research, community referred to all the residents of the following areas:
Boston, Underberg, Cedara, Bushmansnek, Lions River, Impendle, Nottingham Road, Trust Feed, Mpophomeni, Mpolweni Mission, Simons Store and Howick.

- **District.**

In this research , district referred to all the residents of the land demarcated by health, known as District 22(sub-district 222), KwaZulu-Natal.

- **Care Centre/Care and Rehabilitation Centre.**

For the purpose of this research the "Care Centre" and Care and Rehabilitation Centre" have the same meaning.

1.10 THEORETICAL FRAMEWORK OF THIS RESEARCH

Holism is usually associated with qualitative research, but since the needs of the mentally retarded patients are now documented, this research will use the dimensions of the whole person as outlined in the Nursing Theory for the Whole Person and determine to what extent these needs are relevant to this research sample (Oral Roberts University, Anna Vaughn School of Nursing 1990:136).
The research questions and objectives, which needed to explore and describe the physical, emotional, financial, psychological, social, educational, spiritual and cultural needs, the services and facilities available in the community of District 22 (sub-district

222), KwaZulu-Natal, were used as a framework for this study.

1.10.1 Basic assumptions

- Admission to an institution could be prevented altogether if the mentally retarded patient could be cared for in a facility in the community.
- Some of the in-patients could be discharged from the institutions, if they, as patients could be cared for in a residential facility, or special day care centre.
- The admission criteria to institutions could be more stringent or de-institutionalization has to become a greater reality.
- Primary Health Care and institutional care could be deemed as complementing rather than opposing one another if the care and circumstances of some patients and applicants necessitate institutional care while the needs of other patients can be met within the community.
- The criteria for admission to facilities in the community could be revised to become more lenient if the emphasis is being on primary health care.

1.11 RELIABILITY AND VALIDITY OF THE RESEARCH

- **RELIABILITY**

Reliability of an instrument is the degree of consistency with which it measures the attributes it is supposed to be measuring (Polit & Hungler 1997:295). This was achieved in the study by pre-testing the instrument.

- **VALIDITY**

Validity refers to the degree to which an instrument measures what it is supposed to be measuring (Polit & Hungler 1997:299). In this research validity was assured by extensive literature reviews, the researchers own experiences, the opinions of other health team members, the research promoters and a statistician.

Reliability and validity, in research, refer specifically to the measurement of data as these will be used to answer the research questions.

The reliability and validity of the research are discussed in more detail in Chapter 3.

1.12 OVERVIEW OF ETHICAL CONSIDERATIONS

This research involved persons who have diminished autonomy or are vulnerable and less advantaged because of “legal or mental incompetence…..or confinement to an institution” (Burns & Grove 1997:201).

Therefore these people required additional protection of their right to self-determination because they are unable or have a decreased ability to give informed consent. The mentally retarded patient is also vulnerable to "coercion and deception" (Burns & Grove 1997:201). The researcher ensured that no participant was subjected to any physical, emotional, economical, social or legal harm. However this research is justifiable in that insight was gained on the needs of the mentally retarded patients, so as to promote a comprehensive community based psycho-social care and support service, which promotes the psycho-social well-being of individuals and communities as well as allowing such individuals and communities as to develop to their maximum potential which is in line with the de-institutionalization of the mentally retarded patient. The research proposal was presented to the Ethical Committee of the Midlands Complex and to the Department of Health KwaZulu-Natal.

The ethical considerations of this research are described in detail in Chapter 3.

1.13 LIMITATIONS OF THE STUDY

The initial limitation that was identified in this research by the researcher was that the available literature and statistics on mental retardation were outdated.

Limitations will be discussed in detail in Chapter 5.

1.14 OUTLINE (OR STRUCTURE) OF THE DISSERTATION

This research report will have the following chapter layout.

Chapter 2: Literature Review.

Chapter 3: Research Methodology.

Chapter 4: Data Analysis.

Chapter 5: Summary, Limitations, Conclusion and Recommendations.

1.15 SUMMARY

The mentally retarded patients have physical, emotional, financial, educational, spiritual, psychological, cultural and social needs, but no scientific knowledge is known about these needs in the community .

It is therefore for this reason, that research must be conducted, to assess the needs of the mentally retarded patients, the services and facilities in the community of District 22 (sub-district 222), KwaZulu-Natal as no provision is made for the mildly and moderately mentally retarded according to the Mental Health Care Bill (2001:12), so as to make the process of de-institutionalization a success.

In this chapter, an overview of the research was given which highlighted the background, rationale, objectives, assumptions, design and method used and the reliability and validity of the research, an overview was also given on the ethical aspects considered in the research and the scope and the limitations of the study.

In the next chapter, a literature review of relevant sources consulted for the research topic is discussed.